



Intellectual & Developmental Disabilities Task Force

NOTICE OF MEETING AND AGENDA

The Intellectual & Developmental Disabilities Task Force met on Wednesday, April 18, 2018 at 11:00 a.m. (EDT), at the Wabash Center, Inc., 2000 Greenbush Street, Lafayette, Indiana, 47904.

I. **Lt. Governor Suzanne Crouch calls meeting to order (11:00 a.m.)**

a. Introduction of Task Force Members

Note: A special acknowledgement was given to State Representatives Shelia Klinker and Sally Siegrist who were present.

Task Force Members Present: Lt. Governor Suzanne Crouch, Rebecca Kasper, Kim Milas, Jason Meyer, Steve Cook, Kim Dodson, Betty Williams, Kathleen McAllen, Christine Dahlberg, Jonathan Burlison, Kylee Hope, Dr. Pam Wright

Absent: Allison Taylor (Joshua Bougie attended in her place), Terry Stigdon (David Reed attended in her place), Julie Reynolds (Christina Commons attended in her place), Division of Aging Representative, Trent Fox, Joe Langerak, Kevin Moore (David Bozell attended in his place).

II. **Listening Session – Facilitated by Dawn Barngrover, Director of Enrichment Services for the Wabash Center, Inc. (11:05 a.m. – 11:55 a.m.)**

Representative Shelia Klinker. Representative Klinker welcomed everyone. She shared a personal story of her experience of having a sister with Down Syndrome.

Representative Sally Siegrist. Representative Siegrist shared her experience with CASA and participating on the Department of Mental Health & Addiction Task Force.

Charissa Darland, First Steps (Cluster D). First Steps early intervention makes a difference in the lives of those they serve. Gave an overview of services and how the program works and most importantly, teaching the parents to be their child's therapist.

Tammy Frieson, Executive Director, Goldenrod (Elkhart County). Parents navigating the system find it quite challenging. Service providers also find it difficult to maneuver. There is little to no collaboration between teams in education and supportive services. Every provider of services to a child should be at the table to ensure more positive outcomes. A true multidisciplinary approach should not be limited to schools or agencies. Telling a parent whose child is transition age that they can't serve a child until they begin the waiver process is frustrating. More inclusive practices are needed – all systems should be coordinated whether it is in First Steps planning or transition out of high school planning.

Joe Spoelker, Rauch in New Albany, Indiana. Rauch is a First Steps provider in seven counties in Southern Indiana. Over 500 children per year are served. They raised funds to provide therapists with iPads to enhance the therapy sessions. They have seen very positive results. These are used to enhance therapy with technology. He is asking Task Force to consider



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partnering with another group like the Eli Lilly Foundation to provide iPads around the state to other First Steps programs.

Katherine Hargreaves, Early Intervention Program Manager at Easter Seals Crossroads. She has been a provider of services for over 20 years. Easter Seals Crossroads is always looking for skilled clinicians to provide First Steps in their service area who are willing to travel and who are skilled in working with young children and adults. It is becoming increasingly difficult because the rates continue to decline and entry level requirements for physical therapists and occupational therapists are moving from Master level to Doctoral program levels. They rely heavily on part-time, contracted workers. Since 2008, they have reduced First Steps workforce staff by 64% and the number of children served in First Steps is increasing. Approximately 24,000 children are served throughout the state.

Cody Mullen, Twin and co-guardian to his brother Seth who was born with Cerebral Palsy. The instability of direct service professional workforce needs to be addressed. Since June of last year they have lost three DSPs. Two found higher wages and benefits with another employer. Gaps between DSPs is becoming longer and longer. He asks that the Task Force look into this problem.

Lana Renick, Houston Company, (group homes). It is critical that we retain long-term staff. Recommends statewide healthcare for DSPs and increased livable wages.

Renee Peatrie, DSI (Lafayette) and parent to an individual with a disability. The pay scale of Direct Service Professionals is very low. There is often better pay is found at jobs in the mall. Rural communities face challenges of having limited services. Very often they must travel to bigger cities to access services.

Andrea Gilkison, Autism Society of Indiana, Member of the LPCC (local planning committee for First Steps) and a parent of a child with a disability. Andrea shared a personal story about her son, Oliver and her experience with First Steps. The Intake Coordinator sent four therapists to her home for the first three years of her son's life. It was a positive experience working closely with the therapists who empowered her. They helped her to regain control of a situation that was out of control. Oliver is now 9 years old and academically on point with his peers. Their life isn't easy. They rely on the Family Supports Waiver. They use respite and music therapy. It was never a part of their dream to rely on the State to provide the needed services to help their child reach their potential but it is their reality. She needs the Task Force to reach their best potential. Andrea asks that the Task Force create innovative and creative services, increase incentives for recruitment of staff, provide peer related services, pre-teen and teen employment services and streamlined training for all the staff.

Heather Sorrells, IPMG Case Management Services. IPMG provides case management services for the FSW, CIH and Medical Model Waivers since 2016. IPMG surveyed their staff and asked what services are being requested by parents. Therapeutic and respite services are frequently requested and often difficult to obtain and have a lengthy waiting lists. IMPG encourages the



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Task Force to examine the strategies to increase the workforce for licensed music and speech pathologists along with recreational therapists and behavioral consultants. The criteria to receive a CIH waiver should be re-examined. Some families have emergency circumstances that arise but yet they do not qualify for the CIH waiver. At the current reimbursement rate, this limits the amount of help that a case manager can provide. Recommends other methods and forms of media to educate parents.

Patrick Sandy, Chief Executive Officer, Easterseals Crossroads. Since the implementation of Order of Selection for Vocational Rehabilitation, there has been a significant reduction in referrals to providers. For Easterseals Crossroads, this has resulted in a 20% reduction in referrals. He recommends VR adjust the centralized referral process as this is not due to a demonstrated lack of need of service but a systematic issue that has prevented referrals getting through the system. Since implementation of OOS, 886 people were deferred from VR because of OOS. Those individuals are either not receiving services or are referred to organizations who can't support them. Most referred to DWD do not meet the wage requirement to be eligible for DWD services. This has been tried before and has never worked. The move to OOS has resulted in the need for a fresh look at the system that supports payments to providers for providing services to individuals. The current system was developed when different severity levels were being served. With the change to OOS, the system developed doesn't provide adequate compensation to providers. The state needs to figure out how to draw down all the federal match dollars to provide services to persons with disabilities across the state of Indiana.

Wade Wingler, Vice President, Easterseals Crossroads. Wade spoke about the importance of Assistive and Adaptive Technology (AT). Wade read the legal definition of Assistive Technology and then gave his definition: "The tools and technologies that can help make the difference between dependence and independence in the lives of many people with disabilities." He then gave examples of types of AT (wheelchairs, eyeglasses, canes, alternative communication systems). AT is used in nearly every arena of the lives of people with disabilities. Some of this technology is considered healthcare and covered by insurance or Medicaid and some is covered by vocational rehabilitation or employers – order of selection may mean that some people are not referred to high-quality expert providers of assistive technology they need. Other AT is funded out of pocket or sometimes it goes unfunded. This means challenges that can be overcome with the help of assistive technology go unaddressed and this stifles independence. We all live in a time and place where we take technology for granted. When was the last time you tried to get through your day without your eyeglasses, your smart phone or your calendar? As a society, AT use is on the rise as it will continue to grow. He requests that they continue to make funding for assistive technology identification of needs and securing the right equipment a priority. For people with disabilities, access to AT isn't simply a matter of convenience or even efficiency. It is sometimes the critical difference between able to work, travel, learn, communicate and live as independently as possible.



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Savannah Smith, Intense Intervention Special Education Teacher in Elkhart Community

Schools – *Savannah continued with a statement that was started earlier by the Goldenrod CEO.*

She wanted to continue the discussion on the importance of multidisciplinary teams especially with the inclusion movement. Currently, there is not one system that has the level of supports necessary to do this well. Evidence has shown that the possibility of success for all individuals regardless of ability is more likely with a multidisciplinary team approach in a rich, positive, and inclusive setting. We also know that more progress can be made when all systems are coordinated and focused on common goals. Individuals with the most significant developmental disabilities often bring with them behavioral and mental health issues that are complicated and difficult to address. Models like Systems of Care or the LifeCourse wrap coordinated, fully integrated supports and services around the child, the family, the school, the workplace and beyond. If we look at the Systems of Care and the LifeCourse models and find a way to merge the two processes and expand them to include all agencies serving children and adults in Indiana, we will be on our way to achieving the most positive outcomes for all children and their families.

The floor was again opened up to others to make public comment:

Charissa Darland, First Steps (Cluster D) Wanted to give additional information on all the services that Early Intervention/First Steps provides for families. They provide resources and assessments, a service coordinator goes into the client's home and conduct a family assessment. They go through the child's routine and identifies the strengths and needs of the families. Often the find that a family might need assistance with utilities, food, rent, mortgages, and special healthcare assistance. Often therapists are in the home on a bi-weekly basis and are able to help identify the family's additional needs. Every Intervention decreases the chances of a child being abused or neglected. Every child with an open DCS case is automatically referred to First Steps up to the age of 3. Every child who tests positive for exposure to opioids or who has toxic exposure, are automatically eligible for First Steps Services. Team consists of child's doctor, service coordinators, parents, guardians, the assessment team and the ongoing provider. She has two family members who have developmental delays and knows as a family member how important Early Intervention is. She attended college and never intended to get rich from this field but never thought that she wouldn't be able to pay her bills. There has been a 19% increase in referrals but no increase in funding in Tippecanoe County. There is a lot of turnover of people who provide therapy. They have to choose between wanting to make a difference or paying their bills.

III. Review and Approval of Minutes from February 23, 2018 Meeting

- Revised Task Force Vision and Values, as approved at the February 23 Meeting, included in Minutes.

Kim Dodson suggested one correction to insert word "and" on the Vision and Value statement.



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*All Hoosiers with intellectual and other developmental disabilities have opportunities to use their gifts and talents **and** live a good life, with choice and control.*

- Motion to approve Minutes and minutes were approved

IV. **Sample Goals as framework for Task Force Report**

- a. Review and Discussion of Proposed Goals
- b. Consideration of approval of Goals for Report

Kylee Hope gave an overview of ideas for the report with a sample design and format. Steve Cook suggests that they get more specific with timeframes and targets. There was feedback and discussion of the Task Force on sample format. Lt. Governor stated that this is a 10 year plan and it is important that we don't tie short term goals to this as administrations can change and appropriations can change. Lt. Governor Crouch asked Derek Nord with the Indiana Institute on Disability and Community to develop a plan outline for the next meeting.

V. **Updated Agenda, with proposed White Paper topics added**

Steve Cook suggests that the Task Force Member name is added to the White Paper Topics.

VI. **Proposed Data and White Paper Procedures – Rebecca Kasper**

- a. Review and Discussion of Proposed Data and White Paper Procedures
 - b. Consideration of approval of Data and White Paper Procedures
- Motion to Adopt these procedures. Motion seconded and Motion passed.

VII. **Crisis Response White Paper, presented at February 23 Meeting – Review and Discussion**

- a. Review and Discussion of Crisis Response Proposal

Steve Cook and Kim Dodson shared more information to potentially include in the final report.

Recommendation to be included in Report – Motion and Approved.

VIII. **Early Intervention/First Steps**

- a. Indiana First Steps – Christina Commons, Director
Christina gave a comprehensive overview of Indiana First Steps Program.
- b. Patrick Cockrum, Sycamore Services CEO for 22 years. Children's Services
Patrick Cockrum provided input and recommendations to Task Force.
- c. Clare Mann, Director, Northwest Indiana First Steps (System Point of Entry)
Clare Mann provided input on First Steps program.



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- IX. **K–12 Special Education – Dr. Pam Wright, Director of Special Education, IDOE**
Dr. Pam Wright gave an overview of the Indiana Special Education system.
- X. **Postsecondary Options/Higher Education – Teresa Grossi, Ph.D., Director of Strategic Developments, Indiana Institute on Disability and Community (IIDC)**
Dr. Teresa Grossi was asked to attend the next Task Force meeting since the Task Force ran out of time.
- XI. **Next Meeting – Wednesday, June 27, 2018, 10:00 am CT**
Porter County Community Foundation
1401 Calumet Avenue
Valparaiso, IN 46383
- XII. **Meeting adjourned**